

END-OF-LIFE *Care*



Chapter 1

Communication at the End of Life

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Leading the Way in End-of-Life Discussions

Good communication among physicians, patients and their family members is the cornerstone of providing appropriate end-of-life care for patients. Good communication also helps with healthy grieving for family members and physicians. End-of-life communication with patients may be difficult at first, but it is crucial.

Getting started simply amounts to facing up to what is happening. Physicians know their patients' diagnoses and prognoses, and the potential effectiveness (or ineffectiveness) of therapies. Patients know how they feel and are aware of treatment responses. Family members note the effects of illness on their loved one.

It is like the elephant in the living room everyone might prefer to ignore. Getting started with end-of-life communication means dealing with the elephant.

Physicians should lead the way. The most important message physicians can give their patients and families is the assurance they will not be abandoned. The patient and family can then focus on peace and comfort while preparing for death. To effectively consider possible therapy options, patients need accurate, appropriate and timely information about the risks, benefits and burdens of possible therapies. They also need to know what might be expected as death approaches.

Communicate as a Team

Dying is best faced as a team: patient, family, physician and other health care providers. Each team member has unique responsibilities. One role of the physician is to provide adequate and timely information for making treatment decisions. Family members can help loved ones consider the benefits and burdens of treatment options and be allowed to share their concerns.

It is generally accepted that dying patients and their families find satisfaction in activities that provide a feeling of life completion. Research has shown that dying patients often are able to live more fully during this important time of life when they can focus on what is truly important to them. Control of pain and other symptoms is essential. Personal preparation may include making peace with oneself, with others and according to one's spiritual beliefs. It also includes addressing old personal and interpersonal issues and disagreements; and giving and receiving forgiveness and blessings.



Discussing End-of-Life Issues

To have a fruitful discussion about end-of-life issues with patients and families, consider the following:

- Set aside a time and place where the conversation can be held without interruptions.
- Include family members, if the patient desires.
- Encourage the presence of a caring support person whenever possible.
- Provide educational materials about suggested procedures and treatments.
- Discuss advance directives such as the durable power of attorney for health care.
- Discuss treatment options including palliative or hospice care, as appropriate.
- Ask the patient what he or she needs and in what priority.
- Let your patient know you will help achieve his or her end-of-life goals.

Lastly, each team member—including the physician—needs to prepare for a healthful mourning period following a loved one's death. When a physician suppresses the natural grieving process after losing a patient it may lead to emotional withdrawal from issues of care. This can affect relationships and self-image, and may contribute to professional burnout.

General Principles of End-of-Life Communication

Feeling and expressing emotions of love, fear, anger and sadness are normal and inescapable parts of end-of-life communication. They may be experienced alone or in various combinations. The inter-disciplinary care team—including the patient, family, physician and other care providers—needs to recognize and accept that they all will be feeling these emotions and prepare to deal with them compassionately.

Medical information and the manner in which it is delivered can both help and harm patients and families. Physicians should try to determine what information patients and families want to hear and need to know. Sensitively ask how, when and to whom information about the patient's condition should be addressed. Sometimes, when more support is available, additional information will be better received.

Patients and families need information that can be understood, without technical terms, medical jargon or euphemisms. Before talking with patients and families, it may be helpful if physicians rehearse what they want to say, without using medical terms. It is also important to occasionally stop during the conversation and ask whether patients and families comprehend the explanations, or have additional topics they want to discuss.

Usually, patients and families intuitively know when the end of life is approaching. Rather than attempting to absorb more than they are ready to consider and use, it is a good idea to hold several meetings with the patient and family. Meetings can be spaced according to decisions that need to be made and the next one planned at the end of each meeting to avoid feelings of abandonment.

It is important that the patient or any family member feel welcome and comfortable requesting a meeting with the physician to discuss impending personal or medical decisions. Early on, it is valuable to reassess the patient's and family's understandings of what questions are being raised and what new or additional information will be needed.

These meetings can be sacred events, with time for appropriate silence, non-verbal spiritual connectedness, meditation or silent prayer. They provide an opportunity to share emotions, laughter and tears. Traditionally, these have been difficult times for many physicians.

Communicating Prognosis

Patients have various motivations when discussing their prognoses. Some want a sense of their future so they can plan accordingly. Others want reassurance that things are not so serious or hopeless.

When attempting to communicate prognosis:

- Be honest. If you don't know, say so.
- Use averages. (*"One third of people will do well a year from now, half will live about six months. However, you are unique and I don't know exactly what course this disease will take."*)
- Emphasize the limits of predictions. (*"What this will mean for you as an individual no one can be really sure. We can't predict surprises and should plan in case something serious happens."*)
- Reassure the patient you will continue to care for him or her, whatever happens.
- Caution patients and their families that unexpected events can happen. Suggest that they get their affairs in order so they won't be so vulnerable if something unexpected does happen. Use language such as *"What if..."* or *"Let's hope for the best and prepare for the worst."*
- Never tell a patient *"There's nothing more that can be done,"* or *"Do you want everything done?"* Talk instead about the life yet to be lived, and what can be done to make it better (and what might make it worse).
- Sensitively bring up the important subject of advance care planning, as outlined in the next chapter.

When the Dying Patient is a Child

One of the most difficult responsibilities any health care provider encounters is caring for a dying child and the child's family, including siblings. Communicating well with the family and child is particularly crucial, yet may be difficult at first.

Children represent our hopes and dreams for the future, so when a child faces a terminal illness, a normal reaction of both providers and parents may be to fight for

a cure to the very end, all the while knowing the odds of success may be minimal. Appropriate palliative care should be offered throughout the disease continuum, from diagnosis to bereavement. It is important to remember that each end-of-life care decision by the patient, family and care providers is crucial to the child's experience.

A comprehensive web site was developed by the Texas Children's Cancer Center at the Texas Children's Hospital in Houston; www.childendoflifecare.org. This web site offers:

- advice about communicating effectively with families
- information about bridging the transition from aggressive treatment to quality palliative care
- an outline of physical care requirements of children

- suggestions on how to offer supportive care for the family including spiritual, religious and cultural issues
- a support section for health care professionals' own emotions.

Childrens' continuing physical, emotional and cognitive development sets them apart from adults. This influences all aspects of their care, including medications, their understanding of their disease, their communication skills and their level of dependence.

The main caregivers for children are usually parents, with care frequently taking place at home. Parents and siblings will need support throughout the child's illness and their bereavement.

Making Promises to Patients

When you talk with patients who have advanced stages of serious illness, what do you promise them? Symptom relief? Ongoing support? Telephone access to you? All are important to these patients. Physicians might want to take on the challenge posed by Joanne Lynn, MD, who urges doctors and others to make seven promises. Dr. Lynn is the founder of Americans for Better Care of the Dying (ABCD) and was the principal investigator for the SUPPORT study that described experiences of almost 10,000 patients near the end of life and motivated national calls for reform.

ABCD suggests that the next time you meet with a very sick patient and his or her family, try making at least two or three of these seven promises to them:

- You will receive the best of medical treatment.
- We will keep you free from overwhelming pain and other symptoms.
- You will have continuous, comprehensive and coordinated care.
- We will prepare you for everything that is likely to happen in the course of the illness.
- Whenever possible, I will seek out and respect your wishes.
- We will take into account your financial, emotional and practical resources, as well as those of your loved ones.
- We will help you to make the best of every day.

Patients and families need to be able to rely upon their local health care resources, and physicians need to work with others so it is possible to make and keep these promises.

See details about using the seven promises and suggestions for improving care for the dying at www.abcd-caring.org. Refer patients to "The Handbook for Mortals" by Dr. Lynn and take a look at "Improving Care for the End of Life, A Sourcebook for Clinicians and Health Care Managers." Excerpts from both can be read at the ABCD's web site.

Six Steps to Communicating Bad News

Robert Buckman, MD, an oncologist specializing in communication issues, strongly urges physicians to take personal responsibility for the important task of communicating bad news and recommends the following steps be taken.

1. Getting started.

- Plan what will be discussed.
- Confirm medical facts.
- Create an environment conducive to dialogue.
- Allow adequate time and prevent interruptions.
- Determine whom the patient would like present.

2. What does the patient know?

- Establish what the patient knows.
- Assess ability to comprehend bad news.
- Reschedule if unprepared.

3. How much does the patient want to know?

Recognize that people handle information differently, depending on their educational level, ethnicity, culture, religion, socioeconomic status, age and developmental level. Ask the patient and family how they would like to receive information. If the patient prefers not to receive critical information, establish to whom information should be given.

Possible questions might include:

- If this condition turns out to be something serious, how much do you want to know?
- Would you like me to tell you the full details of your condition?
- With whom should I talk about these issues?

4. Sharing the information.

Deliver the information in a sensitive and straightforward way. Avoid talking in a monologue—instead promote dialogue. Avoid jargon and euphemisms. Say the bad news and stop. Silence is a powerful and effective communication tool. Pause between bits of information to check for understanding. Do not minimize the severity of the situation, as it may lead to misunderstanding of your message.

Here is some language that might help in breaking the bad news:

- *“I’m afraid the news is not good. The biopsy showed that you have colon cancer.”*

- *“The report is back, and it’s not as we had hoped. It showed cancer in your colon.”*

5. Responding to family and patients’ feelings.

Patients and families will respond to bad news in a variety of ways. Some respond with tears, anger, sadness and other strong emotions. Others display immediate feelings of guilt, disbelief or shame. Some may try to intellectualize the information. A few may exhibit fight or flight tendencies and may bolt from the room or totally withdraw within themselves.

After the patient and family have had time to react, support them through the broad range of reactions. Listen quietly and attentively, acknowledging their emotions. Help them to identify their feelings, then express empathy. Use language such as:

- *“I imagine this is difficult news...”*
- *“Tell me more about how you are feeling about what I just said.”*
- *“What worries you most?”*
- *“I wish the news were different.”*
- *“Is there anyone you would like me to call?”*

6. Planning and follow-up.

- Plan for next steps (additional information, tests, treatment of symptoms, referrals) as needed.
- Discuss potential sources of support.
- Give contact information, set next appointment.
- Before leaving, assess the safety of the patient and the supports that exist at home.
- Repeat news at future visits.

Note: If there is a language barrier, enlist the assistance of an experienced translator who understands medical terminology and is comfortable conveying bad news. Avoid using family members as primary translators whenever possible.

Adapted from *How to Break Bad News: A Guide for Health Care Professionals*, by Robert Buckman, MD. Reprinted with permission.

Communication Resources

Web Sites

www.childendoflifecare.org—Texas Children's Hospital, Texas Children's Cancer Center – offers a comprehensive site about “End-of-Life Care for Children” and the differences encountered when the dying patient is a child.

www.abcd-caring.com—Americans for Better Care of the Dying (ABCD)—is dedicated to social, professional and policy reform aimed at improving the care system for patients with serious illness and for their families.

Books/Articles

- How to break bad news: A guide for health care professionals. Buckman R. Baltimore: Johns Hopkins University Press, 1992.
- “How to break bad news—And not devastate the patient,” *Mayo Clinical Procedures*, 1994, 69:1015-17, Edward Creagan, MD.
- “Importance of palliative care for children is being increasingly recognized,” Goldman, A., [Letter] *British Medical Journal-BMJ* 2001, 322:234

CD-ROM

- “Completing A Life,” Karen S. Ogle, MD, Palliative Care Education and Research Program, Michigan State University. Information available at www.completingalife.msu.edu

Quotable

“Patients want physicians who will share their humanity with them. They want someone who will listen and show they care, even in the face of death. Making an impact on the quality of life or bringing peace to a distraught family is very gratifying.”

— John W. Finn, MD
Chair, MSMS Committee of Hospice Medical Directors and
Medical Director, Hospice of Michigan, Southfield

“My daughter, Anna, suffers from Leigh's Syndrome, a rare terminal illness. In learning about her prognosis, our pediatric neurologist presented the findings of the tests and then gave us the unfortunate conclusion. While there is no easy way to go about sharing a terminal prognosis with patients and their families, I did appreciate knowing the facts first. After we got the news, a nurse did something that really helped us deal with what to say to our family. She jotted down a few points about Anna's illness and the findings so that we had the information in front of us. It not only helped us process the information, but it also helped us understand what was happening.”

— Kathleen Feeney
Mother of Anna, 10 months

“I have found that we, as health care professionals, are afraid to tell a patient about their case before we know everything. We're afraid of saying the wrong thing. I've found that communicating what we do know and being honest about what we're looking for goes a long way in easing patient anxiety. Patients don't have tolerance for not knowing what's happening. It's when they don't know that their minds begin to make up all sorts of possibilities. We have to respect the patient and communicate the truth.”

— Lauran Bittinger, RN
Hospital Liaison
Hospice of Michigan, Grand Rapids

End-of-Life Care: Talking About End-of-Life Issues

Communicating with Others at the End of Life

Sometimes it is emotionally difficult for family and friends to talk about the future of a loved one who wants to discuss their own wishes as they approach the end of life. It's not easy for anyone, but the benefits are great for all involved when there is open and honest communication. Following are some suggestions for getting started.

Talk about a situation someone else experienced.

One way to begin talking about your wishes is to share a story about friends or relatives who faced a difficult situation. You might say something like: "Do you remember what happened to so and so and what their family went through? I don't want that to happen to me. That's why we need to talk about this now."

Point out the possible consequences of not talking.

Someone may be more willing to talk openly with you if you start by saying: "If we don't talk about this now, we could both end up in a situation that is even more uncomfortable. I'd really hate for that to happen."

Write a letter, or make a cassette tape or video recording.

It may help you and others understand your desires more clearly if you write them down or make a recording. After they read your letter, hear your tape or watch your video, it may be easier for them to talk with you.

Who should you talk to?

Think about the people who are important to you. If you were seriously ill or unable to communicate, who would you want around at this time? It might include family, close friends, clergy, health care providers or caregivers.

What if you don't have close family or friends?

Your best option is to write down your wishes, either as a formal advance directive or personalized statement, or both. Ask your physician for an advance directive form. In addition, you might make a tape or video recording, and share it with your health care providers.

Adapted from the advance care planning workbook, "Your Life, Your Choices" and from the interactive CD-ROM, "Completing A Life."
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